



Carers ACT response to the ACT Government 2015-16 Budget Consultation

Providing housing pathways for people with disability and caring families

October 2014

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We offer our respects to their Elders past and present, and celebrate the Ngunnawal people's living culture and valuable contribution to the ACT community.

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Who is Carers ACT?

Carers ACT is a non-profit, community-based, company limited by guarantee and registered charity dedicated to improving the lives of the estimated 43,000 carers living in the Australian Capital Territory.

These carers provide ongoing unpaid care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to around 8,000 families through our counselling, information, respite support, education, social support and case coordination services. We continue to meet national accreditation standards for delivery of our services to carers at a high level.

Carers ACT also provides carer respite services through the Southern Highlands Commonwealth Respite and Carelink Centre.

Carers ACT has a constitutional mandate to represent the voices of carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing for caring families.

1. Introduction and recommendations

Carers ACT welcomes this opportunity to respond to the ACT Government's 2015-16 Budget consultation.

Carers ACT consulted with a range of carers to prepare its response. It reflects some key concerns for caring families in the ACT, and recognises the financial constraints that the ACT Government faces in the preparation of its next ACT Budget.

Our response focuses on two key areas:

1. Housing for people with physical, cognitive, and psychosocial disability
2. Future planning and housing pathways for people with disability and caring families.

Recommendations

Recommendation 1

Carers ACT recommends that the ACT Government increase its investment in social housing management programs, similar to programs delivered by Capital Community Housing ACT and the Doorways Housing and Support Project, to meet existing and future demand for housing support for people with disability in the ACT.

Recommendation 2

Carers ACT recommends that the ACT Government invest in a Social Housing Gateway for people with disability and low income families as a portal for easy-to-find information to guide their decisions about social housing options, including the capacity to register for a shared housing tenancy and compatible co-tenants.

Recommendation 3

Carers ACT recommends that the ACT Government invest in a Capital Housing Support Program to provide expert advice to caring families who are considering home modifications to their family home, or the purchase of a new property or accessing equity in their family home to provide suitable and secure housing tenure for their family member or members with disability.

Recommendation 4

Carers ACT recommends that the ACT Government invest in a program with ACT organisations, such as the Real Estate Institute of the ACT, banking and financial institutions, building companies, the community housing sector and other key stakeholders to generate support within the community to provide housing pathways for people with disability in the ACT.

Recommendation 5

Carers ACT recommends that the ACT Government work closely with the Australian Government and the National Disability Insurance Agency to investigate and develop appropriate housing options under the National Disability Insurance Scheme including

housing modifications, user cost of capital funding or Special Disability Trusts to provide increased 'choice and control' for secure and long-term housing for people with disability.

Recommendation 6

Carers ACT recommends that the ACT Government invest in re-funding the Good Life Planning Grants program, or a similar program, to support people with disabilities and their caring families plan a housing and care support pathway to provide long-term certainty about housing tenure, transition planning and necessary legal and other specialist advice. The investment should include funding to broker or provide legal and other specialist advice for caring families who are unable to meet these costs.

2. Housing for people with physical, cognitive, sensitive and psychosocial disability

Housing continues to be a primary concern for Carers ACT members and their families caring for a person with a disability (physical, cognitive, sensitive and psychosocial). The need for secure, affordable and sustainable housing has been a constant priority for family carers in Carers ACT's past three ACT Government Budget Submissions, and was the catalyst for the Carers ACT 2012 Supported Living Summit.¹

There is an undersupply of social housing² relative to need in the ACT and limited housing options available in the private rental market.³ This situation is common to other jurisdictions across Australia.

Over recent years several reports, strategies and inquiries have addressed policy and funding issues to improve this situation. These include the Senate Economics References Inquiry into Affordable Housing, which has had its report date extended until 27 November 2014. Regardless of the outcomes of this inquiry and other activities, such as the National Affordable Housing Agreement⁴ there will be a considerable time lag between this increased policy intent and availability of sufficient housing to address the unmet need.

The National Housing Supply Council estimated that there was a shortfall of 228,000 dwellings in Australia at June 2011, and this will increase to 431,000 dwellings by 2028. For people with disability and their caring families this time lag will extend the length of time the caring family's home provides accommodation for an adult family member with disability.⁵

¹ Carers ACT (2012) Carers Summit on Supported Living Options Final Report, March 2012.

² Social housing is a term used to include public and community housing. Public housing is funded by government, and community housing is provided by community housing organisations funded by the ACT Government.

³ ACT Shelter (2012) Improving access to private rental and sustaining private rental tenancies for people experiencing, or at risk of, homelessness in the ACT, Canberra.

⁴ The National Affordable Housing Agreement is an agreement by the Council of Australian Governments that commenced on 1 January 2009, initiating a whole-of-government approach in tackling the problem of housing.

⁵ It is understood that individual family situations differ and that choice must be a consideration when seeking accommodation solutions. While some adults with disability will choose to continue to live in the family home

That Canberra has one of the highest cost housing, second to Sydney, of all capital cities in Australia; a low private housing rental vacancy rate; and a waiting period for public housing⁶ adds to the need for appropriate programs and policies to address housing for people with disability in the ACT.

In 2011-12 approximately 70 per cent of ACT households either owned their home outright or owned their home with a mortgage. Approximately 23 per cent of households in the ACT rented from private landlords and around 7.5 per cent of households rented from a public housing authority.

Nationally housing costs have increased significantly between 1994-95 and 2011-12 with the highest weekly increase⁷ for private renters (57%), owners with a mortgage (43%), and public renters (40%) who experienced the lowest increase. Lower income private rental households paid an average 30 per cent of their gross weekly income, while all private renters paid an average of 20 per cent.⁸

Many people with disability living with their caring family with the Disability Support Pension as their main source of income, or part time employment supplemented by a part pension, will need to compete in this tight rental market to realise their aspiration to live independently in the community. This fact challenges the premise in NDS ACT's *Housing and Support for People with Disability under the NDIS: A report and review from the ACT* that people with disability should not have fewer options for security of tenure than the general population.⁹

According to Bruce Bonyhady AM, Chair National Disability Insurance Agency (NDIA), access to suitable and stable housing is critical to the wellbeing of people with disability and the vision of the National Disability Insurance Scheme (NDIS), but there are few housing options and limited housing careers for people with disability today because:

1. The cost of support when living independently
2. Private housing is unaffordable for most people with disability.

Around 410,000 people nationally, including 57,000 people with psychosocial impairment, are anticipated to become NDIS participants. Of these participants 57,000 are living in social housing, and there is an estimated 83,000 to 122,000 unmet affordable housing need for participants.¹⁰

with the support of their parents, for other people with disability and their caring families their aspiration is to live independently in affordable, safe and sustainable housing similar to peers without disability.

⁶ At 1 September the ACT Government Social Housing Waiting List for approved applications was: 133 days (priority housing with 164 applications), 713 days (high needs housing with 1418 applications) and 770 days (standard housing with 699 applications).

⁷ Adjusted for inflation.

⁸ Australian Bureau of Statistics (2013) *Housing Occupancy and Costs, 2011-12*, Canberra.

⁹ NDS (2013) *Housing and Support for People with Disability Under the NDIS: A report and review from the ACT* November 2013, Canberra.

¹⁰ Bonyhady B (2014) *The National Disability Insurance Scheme: A catalyst for scalable, affordable and accessible housing for people with disability*, presentation to the Community Housing Federation of Australia Conference, Canberra, 27 March 2014.

Key to the ACT Government's housing direction for people with disability is the need to investigate and adopt different ways to meet this housing need in the ACT, including partnering with philanthropic organisations or private sector developers, coordinating housing and disability forums for service providers and other key stakeholders, liaising with the Real Estate Institute of the ACT and consulting with individual families about the best transition plan for their family members with a disability from ACT Government housing to community or private sector housing.

Currently, the ACT Government is undertaking:

- A Review of the Residential Tenancies ACT 1997 (ACT) and is still to report the findings of the review. The review addressed four areas: Fairness, Sustainability, Share house tenancies and Improvements in rental housing stock. It included both ACT Government housing (or social housing) and private housing.
- Implementation of its Public Housing Asset Management Strategy, which includes progressive re-development of ageing housing stock and several multi-unit properties.

These actions are timely as the ACT Government has indicated it is currently unable to provide sufficient housing to meet the need of people with disability, and people with disabilities and their families will need to consider private rental as a housing option.

The expectation that people with disability become private rental tenants:

- is in variance to several key ACT Government housing frameworks and discussion papers
- is inconsistent with understanding on long term housing preferences and expectations of people with disability and their family carers.

For carers and the person with disability they care for this situation is exacerbated by uncertainties about the NDIS and housing. A Community Housing Federation of Australia forum on this issue noted that "no matter how well funding from the National Disability Insurance Agency is leveraged the demand for housing from people with disability will almost certainly exceed supply for many years to come".¹¹

Along with the focus on the NDIS and housing it is important that the ACT Government continue housing provision to people with disability who are ineligible for the NDIS.¹² For example, extensive Australian and international research and anecdotal evidence indicate that people with mild

¹¹ Community Housing Forum Australia (2014) Housing, Disability, and the NDIS: forum communique, March 2014.

¹² NDIS Tier 3 eligibility requires that the recipient has significant, ongoing impairment or functionality. The anticipated ACT NDIS Tier 3 population is likely to exclude Canberrans with mild disability. Evidence indicates that people with mild intellectual or psychosocial disability are often excluded from disability services and priority public or community housing as their 'mild impairment' classification can mask their support needs because of their assessed functionality. They are less likely to access or continue to engage with services, can lack informal support as their families struggle to support them because of challenging behaviour and other issues, and are vulnerable to abuse and exploitation.

intellectual or psychosocial disability (a population group that is unlikely to receive an NDIS package) had high risk indicators for homelessness.¹³

ACT Government accommodation frameworks and discussion papers

As indicated above, ACT Government documents outline its rationale for providing social housing to different ACT population groups, including people with disability.

Future Directions: Towards Challenge 2014 is the ACT Government's policy framework for people with disability in the ACT. It states that the ACT community's vision is that all people with disabilities achieve what they want to achieve, live how they choose to live, and are valued as full and equal members of the ACT community. By 2014, adults with a disability should be able to:

- be recognised as adults first with similar needs to other adults
- fulfil their need to develop or maintain intimate relationships and to enjoy loving relationships with partners and family if they wish to do so
- have a place they can call home
- access a variety of options for affordable and high standard housing.¹⁴

The ACT's *Public Housing Asset Management Strategy* asserts the ACT public housing priority will be about providing housing and community services to the most vulnerable members of the Canberra community. Under the strategy, affordability issues for public housing tenants will no longer be the key driver for eligibility for public housing by themselves and will be considered in conjunction with one or more issues, including:

- mental health or medical issues¹⁵
- disability, including frail-aged carers.¹⁶

The ACT Government's Social Housing Discussion Paper on current ACT social housing residential tenancy issues produced for the Review of the Residential Tenancies Act 1997 (ACT) states:

There are a number of emerging significant reforms and issues that are likely to alter the housing experience for diverse cohorts, such as people with disability, and social housing tenants. Key service reforms, especially the National Disability Insurance Scheme (NDIS), the

¹³ Speakers Professor Andrew Beer Director of the Centre for Housing Urban and Regional Plan, expert on housing and disability and housing and wellbeing; and Mr Gerald Franks Director of Community Services Canberra Men's Centre at the Community Services Directorate *Enabling Housing Design Forum*, 24 September 2014 cited research and case studies to support this premise. The Canberra Men's Centre supports men in the ACT living with complex needs, including homelessness. Professor Beer's publications are available at <http://www.adelaide.edu.au/directory/andrew.beer#Publications>.

¹⁴ ACT Government (2009) *Future Directions: Towards Challenge 2014*, Canberra.

¹⁵ In previous budgets the ACT Government committed funds to the development of Common Ground in Canberra to provide housing for people at risk of homelessness, including mental illness. Common Ground was supported by a dedicated group of Canberrans who strongly advocated for this housing model in the ACT. Similarly, the My Home in Canberra board and community members are advocating that another housing model for people with mental illness be developed in the ACT with the support of the ACT Government and the community.

¹⁶ ACT Government (2012) *Public Housing Asset Management Strategy*, January 2012. Accessible at http://www.communityservices.act.gov.au/hcs/public_housing_asset_management_strategy

Human Services Blueprint, and changes to the aged care system, will impact on the housing needs and services accessed and provided through the social housing system.¹⁷

Public housing in the ACT is targeted more than any other Australian jurisdiction. In 2012-13, 98 per cent of new Home and Community Services ACT tenants were households on the high and priority needs waiting lists. This means that tenants have higher and more complex needs and are more likely to remain in income support. Around 90 per cent of public housing tenants are on a rental rebate.

Just over half of renting households (including share houses) in the ACT private rental market have an income in the middle to high income quintiles.¹⁸ Canberrans with lower incomes are likely to have difficulty securing a tenancy in the private rental market because they are competing for rental properties against higher income earners.¹⁹

Because of this situation Housing and Community Services ACT is undertaking reforms within this context to consolidate its role as a social housing provider within a human services framework. This shift also includes an increased focus on housing the highest needs tenants with the lowest incomes, including people with disability, and may require different tenancy management services depending on their needs.²⁰

As indicated above, shared housing is one of the four areas addressed by the Review of the Tenancies Act 1997 (ACT). While shared housing provides the opportunity for people with disability on low incomes to live independently from their family in a private rental property, it will create anxiety for some people with disability and their carers and families about:

- reduced tenancy security, that may be subject to the sale of the property, breakdown in shared house arrangements if one tenant leaves the shared house and other issues
- suitability and proximity of available private rental properties to public transport, medical centres, shopping centres and facilities that provide social engagement
- discrimination by landlords and real estate agents towards people with disability, particularly if more than one tenant in a shared house has a disability²¹
- legal uncertainties about private or shared house tenancy agreement or leases and their termination
- reduced opportunity to transfer to a preferred public housing option.

¹⁷ Accessible at www.justice.act.gov.au under Reviews.

¹⁸ This is due to the high level of public servants in Canberra and the large number of tertiary students who can afford to share houses, or maintain private rental tenancies at the market rate.

¹⁹ The Australian Bureau of Statistics 2012 Survey of Disability and Ageing indicated that carers and their households are over-represented in the lower income quintiles, and people with disability are also among those with lower incomes in the community.

²⁰ ACT Government (2014) Review of the Residential Tenancies Act 1997 (ACT) Social Housing Discussion Paper, July 2014.

²¹ It is illegal for landlords or property managers to eliminate potential tenants because of discrimination. However, there is evidence that people with disability and low income experience discrimination and exclusion as 'risky' tenants in private rental housing. See the 2008 Australian Housing and Urban Research Institute report, Risk-assessment practices in the private rental sector: implications for low income renters.

According to ACT Shelter, tenants often have a limited awareness of their legal rights as tenants, or if they are aware of these they are often unwilling to act on these rights for fear they will jeopardise their housing situation. The housing affordability challenge for low to moderate income earners is accompanied by the challenges of accessing housing that is safe, appropriate, and that offers security of tenure.²² This is true for many people with disability and their caring families.²³

Housing preferences of people with disability and their caring families

Carers ACT consultations with caring families of people with disability, housing papers by other Carers Associations and independent researchers indicate the importance of safe, appropriate housing with secure tenure for the person they care for one when they are no longer able to continue, or chose to cease, their caring role because of their own ill health or increasing frailty.

A recent literature review by the Home Modification Information Clearinghouse, City Futures Research Centre, University of New South Wales provides an insight into the housing situation, and housing needs and preferences of caring families. Key findings included:

- Young people with disability typically live in the family home for much longer periods of time than people without disability due to the lack of suitable housing and support services for them to live independently.²⁴
- People with a disability face enormous difficulties leaving the parental home and finding alternative accommodation, which means many stay in the parental home well into middle age.
- Adults who acquire disability often need to return to their parents' home because of limited alternate housing options.
- The lack of suitable housing for people with disability is a barrier to effective planning by ageing parent carers for the future needs of their adult children with disability.
- Parent carers identified the lack of appropriate and desirable [public] housing as a limiting factor in planning for the future.²⁵
- 66.9% of carers live in their own home with or without a mortgage, while the rest live in various forms of rental homes, including social and private housing.
- Modification of the family home can provide independence for the family member with disability, as well as reduce the stress and injury of the carer.²⁶

In its submission to the Victorian Government's social housing framework Carers Victoria said:

²² ACT Shelter (2012) *ibid*.

²³ As at March 2014, there were 8,787 people in the ACT receiving the Disability Support Pension; 1,283 receiving the Carer Payment and 5,424 receiving the Carer Allowance. Source www.data.gov.au.

²⁴ Productivity Commission (2011) *Disability Care and Support*, Report No 54, Canberra.

²⁵ Petriwyskiy A, Franz J and Atkins B (2012) *Long-term planning and housing for lifelong participation and wellbeing: An exploration with parent carers for people with disabilities*.

²⁶ Davy L, Adams T and Bridge C (2014) *Caring for the Carer: Home design and modification for carers of young people with disability*, July 2014, University of New South Wales.

There are several ways in which housing is of particular importance to carers. The lives of family carers are intrinsically linked with those people with a disability that they care for. In the vast majority of cases, family members naturally want the best for their family member and are concerned about the difficulties they face in accessing appropriate housing.

Caring relationships involve interdependency. In this context, this means that family members are also affected in very direct ways by the housing options available to the person they care for. If a person with a disability and/or mental illness cannot access public housing, this can not only impact on their wellbeing, but that of the entire household.²⁷

Carers have a strong preference for home ownership because it is considered to provide security of tenure for the person they care for and increased capacity to undertake home modifications as required. Sixty five per cent of carers in an Australian Housing and Urban Research Institute study on housing of people with a disability and carers of people with disability were outright owners of their home. This was often at the sacrifice of accumulating other assets, such as superannuation.

Carers purchasing houses were more likely to be in mortgage stress than other home owners. Contributors include – unpaid caring families have much lower levels of paid employment and level of income than other Australians of similar age because of the difficulty in balancing caring and employment,²⁸ and many Australian families require dual incomes to afford and sustain mortgage payments.

Carers ACT focus groups with carers of people with disability²⁹ indicated that although social housing was the preference for the majority of carers in the focus groups (particularly mature aged carers) carers were willing to consider private rental as an alternate housing option if there was support for them to establish a suitable tenancy. This included assistance to choose compatible co-tenants for a shared house, and an agency or provider to manage tenancy agreements and rental and bond payments. They anticipated that individual support packages provided by the NDIS or the ACT Government (for non NDIS Tier 3 participants) will be required to help the person they care for live independently, including support to transition to independent living. Targeted financial assistance, such as the Commonwealth Rent Assistance or ACT Housing Bond Loans Scheme, is also likely to be required.

Existing programs that provide this tenancy management support, for example Capital Community Housing in the ACT and the Doorway Housing and Support Project for people with mental illness in Victoria, demonstrate the benefits to governments investing in this type of program.

²⁷ Carers Victoria (2012) Submission to the Pathways to a new Victorian social housing framework, August 2012. Accessible at <http://www.carersvictoria.org.au/Assets/Files/submission%20social%20housing%20framework.pdf>.

²⁸ Beer A and Faulkner D (2009) The housing careers of people with a disability and carers of people with a disability, Australian Housing and Urban Research Institute.

²⁹ Carers ACT conducted three carer focus groups: carers of people with mental health issues, carers of children with disability, and mature aged carers of adult children with disability during September 2014 to inform our budget response.

- **Capital Community Housing ACT** www.capitalcommunityhousing.org.au
Capital Community Housing is an ACT registered community housing provider. It has provided housing services for people with disability for over 30 years, and is recognised as “... one affordable housing provider, which is a growth provider of housing for purchase as well as rental properties”.³⁰ It offers clients choice and options for housing through four different programs. Seventy-five per cent of clients are in its Housing with Funded Support program, 13 per cent are in its Independent Living program, 8 per cent in its Single Share program and 4 per cent in its Family as Carers Housing program.

In 2012-13 Capital Community Housing ACT supported 126 clients and had 66 properties in its property portfolio.³¹

Capital Community Housing ACT is also considering the development of a housing gateway where individuals and caring families can register their interest in sharing a house, housing providers can include details about their property services and other information to support rental decision making.³²

- **The Doorway Housing and Support Project** <http://www.mifellowship.org/content/doorway>
Doorway is a unique and innovative housing and support demonstration project for people with mental illness who have been unable to secure adequate and stable housing. It was funded for three years up to June 2014 by the Victorian Government and delivered by Mental Illness Fellowship Victoria. As well as addressing the immediate housing needs of participants, Doorway supports participants through Housing and Recovery Workers to develop long term skills. Participants are involved in every part of the tenancy process from house-hunting and preparing rent applications, to liaising with real estate agents. Importantly, 27 real estate agencies participated in the program.

Doorway participants contributed 30 per cent of their household income towards their rent, excluding their Commonwealth Rent Assistance. Doorway provided time-limited top-up payments for each person’s fortnightly rental.

A Nous Group Doorway project longitudinal three-year evaluation indicated positive outcomes for participants. Health and housing outcomes were the greatest gains. Other outcomes included increased engagement in paid and unpaid work, and the ability to achieve stable and secure private rental accommodation.

³⁰ ACT Shelter (2012) *ibid*.

³¹ These figures are likely to have changed in 2013-14 due to normal business operation, and the transition of ACT Government disability housing tenants to the non government sector.

³² The concept of a social housing gateway has been discussed in several forums, and is supported in the NDS Housing and Support for People with Disability Under the NDIS: A report and review from the ACT November 2013. Caring families in recent Carer ACT focus groups also supported this recommendation.

Recommendation 1

Carers ACT recommends that the ACT Government increase its investment in social housing management programs, similar to programs delivered by Capital Community Housing ACT and the Doorways Housing and Support Project, to meet existing and future demand for housing support for people with disability in the ACT.

Recommendation 2

Carers ACT recommends that the ACT Government invest in a Social Housing Gateway for people with disability and low income families as a portal for easy-to-find information to guide their decisions about social housing options, including the capacity to register for a shared housing tenancy and compatible co-tenants.

As identified above, carers often invested in the purchase of their own home or, if they were able, purchased a separate property to ensure housing security for the person they cared for.

Several carers in our recent focus groups indicated their interest in investigating the purchase of a property for the person they cared for using equity in their own home. Their considerations included that the property be purchased independently, as a mixed-equity property with the person with disability or family members, or jointly purchased with other families. At least one carer had purchased a separate property for their adult child with disability.

Outcomes from the Carers ACT 2012 Supported Living Summit³³ as well as our recent focus groups with caring families indicated that many would contribute financially to the cost of appropriate accommodation for their family member(s) with a disability. Some are considering or have undertaken innovative solutions such as ‘pooling’ individual support packages and other income to build, purchase or lease single accommodation or a group home. Other carers indicated their interest in investigating housing options with the support of expert advisors.

Recommendation 3

Carers ACT recommends that the ACT Government invest in a Capital Housing Support Program to provide expert advice to caring families who are considering home modifications to their family home, or the purchase or a new property or accessing equity in their family home to provide suitable and secure housing tenure for their family member or members with disability.

Recommendation 4

Carers ACT recommends that the ACT Government invest in a program with ACT organisations, such as the Real Estate Institute of the ACT, banking and financial institutions, building companies, the community housing sector and other key stakeholders to generate support within the community to provide housing pathways for people with disability in the ACT.

³³ Carers ACT (2012) *ibid*.

The role of the NDIS in housing

The role of the NDIS and housing support and the contribution of state or territory governments to support NDIS housing outcomes are uncertain.

While the NDIS does not explicitly include provision of accommodation, NDIS Rules: *Supports for Participants* under Rule 7.19 states the NDIS will be responsible for a range of supports to assist a person with disability live independently in the community, home modifications for accessibility in private and legacy public and community houses, and user costs of capital in some situations.³⁴

Importantly, the City Futures Research Centre literature review also looked at the suitability of a carer's home, which is the 'workplace' where people with disability receive most of their care. The authors stated:

Carers work in [by providing care], and usually live in, the home which may not be designed to support them in their caregiving role. To assist them in their role, carers may require modifications to their home to make them safe to work in and enabling for the person with disability to reduce workload on the carer.

Judicious investment by the NDIS and governments in home modification to enable a person with disability remain in the family home, if this is their choice, with the support of their family extends or eliminates the time before transition to social or private housing.

Bruce Bonyhady AM NDIA Chair said that "the NDIS can be a catalyst for new accessible housing" by working with participants and families through:

- housing models that identify opportunities for participants and families to contribute to housing security through shared equity models
- promoting the benefits of mixed equity models with people with disability in achieving 'home ownership like control'
- overcoming barriers to families contributing capital to shared equity models, including determining a reasonable contribution
- facilitating the development of standard mixed equity and tenancy agreements and examining the potential role of Special Disability Trusts
- utilising the proposed NDIS capital funds (estimated at \$550 million per annum in current dollar terms) for the 'user cost of capital'.³⁵

KPMG stated in its interim review of the NDIS that access to housing was one of the key areas where further work is required to underpin the full scheme design, particularly lead times required to deliver housing services to participants.³⁶

³⁴ Australian Government (2013) National Disability Insurance Scheme Rules – Supports for participants, February 2013.

³⁵ Bonyhady B (2014) *ibid*. Note Bruce Bonyhady updated this to \$700 million per annum in an August 2014 presentation.

³⁶ KPMG (2014) Interim Report: Review of the optimal approach to transition to the full NDIS, 16 July 2014, Sydney.

The release of the NDIS Housing Discussion Paper is expected to provide greater direction to government, accommodation providers and people with disability and caring families on housing solutions.

Recommendation 5

Carers ACT recommends that the ACT Government work closely with the Australian Government and the National Disability Insurance Agency to investigate and develop appropriate housing options under the National Disability Insurance Scheme including housing modifications, user cost of capital funding or Special Disability Trusts to provide increased 'choice and control' for secure and long-term housing for people with disability.

3. Future planning and housing pathways for people with disability and caring families

A significant concern for carers supporting family members with disability is the question: Who will look after the person I care for when I am no longer able to care for them?³⁷ Section 2 above includes a broad discussion about the interdependency between people with disability and their caring family, including the role of the family home in providing housing sustainability; and the limitations low level of household income and assets, and lack of expert information to facilitate the transition to independent living for family member(s) with disability.

Caring families have informed Carers ACT through consultations or one-on-one discussions of their desire to initiate a future plan for the person they care for. In tandem with the need for appropriate, safe and secure housing was the required transition so caring families are better able to support family members make this transition. This includes:

- Support with legal and financial planning – including wills and estate planning, special disability or family trusts, contracts for family property management, and planning ongoing representation arrangements for the person with a disability.

We are aware that at least 15 caring families have used or are planning to use Disability ACT's Enhanced Service Offer for future planning. This demonstrates that caring families are willing to undertake future planning if they have the financial resources to do so.

Funding for the ACT Government's Good Life Planning Grants has ceased. Among the elements of the grants were "... conferences and coordinator for long-term planning and to develop family designed or governed responses to achieve personal aspirations for a good life".³⁸

³⁷ Carers ACT (2012) *ibid*.

³⁸ ACT Government Good Life Planning accessible at http://www.communityservices.act.gov.au/disability_act/functions/financial_assistance_and_benefits/good_life_planning_grants.

However, in Carers ACT's discussions with the NDIA it is not clear whether long-term future planning is included in the schedule of prices. Access to future planning services for caring families when the family member is not eligible for an NDIS Tier 3 package is also unclear.

Another service to assist caring families and people with disability is the ACT Government's Housing Options planning service. A Housing Options Facilitator is available to assist individuals and families to navigate their way to a housing outcome. The service does not provide funding to purchase or broker services, such as preparation of legal documents; or accommodation support allocation.³⁹

Recommendation 6

Carers ACT recommends that the ACT Government invest in re-funding the Good Life Planning Grants program, or a similar program, to support people with disabilities and their caring families plan a housing and care support pathway to provide long-term certainty about housing tenure, transition planning and necessary legal and other specialist advice. The investment should include funding to broker or provide legal and other specialist advice for caring families who are unable to meet these costs.

4. Final comments

For many carers and their households their ongoing caring responsibility is extremely challenging. It can include financial hardship,⁴⁰ uncertainty about NDIS eligibility and adequate service provision, the need to make future decisions on the person they care for – those with a disability, a chronic illness or who are ageing – and other issues that non caring families don't regularly face.

The Carers ACT Budget 2015-16 Consultation response focuses on two key issues for caring families and their family members with a disability – housing and future planning. Through our involvement in pre-budget forums and discussions with colleagues and other non government organisations we contributed to the direction of their budget responses, and we support their recommendations to improve the quality of life for caring families in the ACT

³⁹ ACT Government Housing Options information accessible at <http://www.communityservices.act.gov.au/search?query=housing+options>.

⁴⁰ Carers are concentrated in the lowest income distribution quintiles. In particular, 22.9 per cent of carers who receive an allowance and 32.3 per cent of carers on other payments who live in households where there is a person receiving an allowance are in the poorest 10 per cent of Australian households. The negative impact on households where both the carer and another person received government income support (e.g Disability Support Pension) meant 31.6 per cent needed to approach welfare or community agencies for help, over half sought financial support from family and friends; and 60 per cent were unable to pay an electricity bill on time. (Data from the 2009 Household, Income and Labour Dynamics in Australia (HILDA) Survey.)